How do women seek information about potential breast cancer symptoms? Capturing online behaviour with an Internet browser tracking tool

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Using the Internet for health information

- one percent of Google searches – the equivalent of millions of searches – are symptom-related (Pinchin, 2016)

- **self-diagnosis** is a common reason for seeking health information online (Moore et al., 2012; Thomson et al., 2012)

- people consult the Internet to appraise **potential cancer symptoms** before seeing the family doctor (McLeod et al., 2016) or the oncologist (Castleton et al., 2011)

- **breast cancer** is one of the most frequently searched for cancer topics online (McHugh et al., 2011; Foroughi et al., 2016)
  - topic of interest
  - correlates with awareness campaigns
  - reflects high incidence of breast cancer
Implicit assumptions and challenges

Ability needed to:
  • articulate bodily changes into effective search terms
  • locate relevant sources of health information online
  • interpret online health information appropriately

Challenges:
  • online info sources on breast cancer can vary in quality and completeness (Ream et al., 2009; Warren et al., 2014)
  
• women who seek info about breast-related symptoms can feel uncertain about how to appraise the information found online (Marcu et al., 2017)

Need more research on:
  • how people translate symptoms into online info-seeking strategies
  • whether online info-seeking helps understanding of symptoms
The present study

How do women seek information online about potential breast cancer symptoms?

**Design:**
- online vignette survey
- VIZZATA browser tracking tool
- DuckDuckGo search engine

**Outcomes:**
1. symptom attribution
2. online behaviour:
   - search terms
   - websites accessed

Symptom vignette – nipple rash (Marcu et al., 2016):

*One morning, while having a shower, you notice a red scaly rash on your left nipple. You are not sure if there is anything unusual about the rash. You check the other nipple and it looks fine. Apart from this change, you have not noticed anything about your body that is different from usual.*
Participants

- 56 women from across the UK, mean age = 60, age range = 50 to 78
- no current diagnosis of breast or other cancer

- no formal qualifications: 12 (21.4%)
- education below degree level: 20 (35.7%)
- education at degree level or above: 24 (42.9%)

- past online search:
  - nipple rash: n=3 (5.4%)
  - breast cancer: n=20 (35.7%)

- 33 (58.9%) had searched for health information relatively recently, but not for nipple rash or breast cancer
The tracking tool interface
The tracking tool with instructions to participants

Do not type search terms in the address bar

Type search terms here

Already a fan? Help Spread DuckDuckGo!

Do not type search terms here
## Symptom attribution at T1 (prior to search task)

<table>
<thead>
<tr>
<th>Type of attribution</th>
<th>T1 (before Internet search task)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>25 (44.6%)</td>
</tr>
<tr>
<td>Physical</td>
<td>26 (46.4%)</td>
</tr>
<tr>
<td>Environmental</td>
<td>16 (28.6%)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>7 (12.5%)</td>
</tr>
<tr>
<td>Missing attribution</td>
<td>2 (3.6%)</td>
</tr>
</tbody>
</table>

- 85.8% (48/56) found the scenario *fairly* to *very easy* to imagine themselves in
- 53.6% (30/56) made a single symptom attribution at T1
- 86% (48/56) intended to use rash-related phrases (e.g. ‘nipple rash’, ‘nipple red rash’, ‘red scaly rash on nipple’)
- 3 participants intended to use ‘breast cancer’ and 1 participant, ‘skin cancer on the breast’
Search terms used

• no search terms were captured for 10 participants

• only 2 participants used cancer-related search terms
  • breast cancer symptoms
  • what are the chances of red scaly rash on nipple being cancer

• 40/46 (87%) used rash-related search terms, in particular:
  • ‘nipple rash’ 7/46 (15.2%)
  • ‘red scaly rash on nipple’ 8/46 (17.4%)

• some participants added sensorial terms to the search:
  • ‘itchy rash on nipple’ 2 (4.3%)
  • ‘itchy red breast rash’ 1 (2.2%)
  • ‘what should I do if I suspect I have itchy nipples’ 1 (2.2%)
  • ‘sore nipples’ 1 (2.2%)
Websites accessed

- no websites were recorded for 10 participants

- 5/46 participants (9%) did not go beyond the page with search results returned by the search → these were coded as 0
- the number of websites visited ranged from 0 to 6

- 41/46 (89%) viewed websites containing breast cancer information

Most accessed websites:

- www.nhs.uk – Paget’s disease of the breast 21/41 (51.2%)
- www.skinsight.com 8 (19.5%)
- www.rightdiagnosis.com 7 (17%)
- www.webmd.boots.com 7 (17%)
- symptoms.rightdiagnosis.com 6 (14.6%)
## Symptom attribution at T2 (after search task)

<table>
<thead>
<tr>
<th>Type of attribution</th>
<th>T1 (before Internet search task)</th>
<th>T2 (after Internet search task)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td>25 (44.6%)</td>
<td>37 (66.1%)</td>
</tr>
<tr>
<td>Physical</td>
<td>26 (46.4%)</td>
<td>32 (57.1%)</td>
</tr>
<tr>
<td>Environmental</td>
<td>16 (28.6%)</td>
<td>3 (5.4%)</td>
</tr>
<tr>
<td>Don’t know</td>
<td>7 (12.5%)</td>
<td>4 (7.1%)</td>
</tr>
<tr>
<td>Missing attribution</td>
<td>2 (3.6%)</td>
<td>2 (3.6%)</td>
</tr>
</tbody>
</table>

- 55.4% (31/56) made a single attribution at T2
- 6 changed from a cancer attribution at T1 to a non-cancer attribution at T2
- Increase in medical terms in symptom attributions at T2 compared to T1:
  - *Paget’s disease* (22 vs. 1)
  - *eczema* (14 vs. 8)
  - *dermatitis* (12 vs. 3)
  - *mastitis* (3 vs. 0)
Antecedents of cancer attribution at T2

• no association between viewing websites with cancer content and making a cancer attribution, $x^2(1, 46)=1.92, P=0.311$

• participants who attributed the symptom to cancer at T2 (M=4.03, SD=0.80, n=37) reported significantly higher levels of systematic processing of the information found online than those who did not (M=3.54, SD=0.71, n=19), $t(1,54)=2.26, P=0.028$

• systematic processing was positively correlated with e-health literacy, $r=0.54, P<0.001$

• no significant difference in e-health literacy between the participants who made a cancer attribution at T2 (M=3.91, SD=0.65, n=37) and those did not (M=3.60, SD=0.68, n=19), $t(1,54)=1.83, P=0.073$
Summary and conclusions

• not all cancer symptom attributions translated into cancer-related search terms

• viewing websites containing breast cancer information did not always lead to attributing the nipple rash to cancer
  • depth of information-processing is important, not just exposure to information
  • not all participants may have scrolled down to the relevant information on websites

• searches were mostly inductive (driven by symptoms) rather than deductive (driven by diagnosis assumptions, e.g. cancer, eczema)

  evidence-gathering rather than hypothesis-testing (cf. Perez et al., 2015)
Implications for research and practice

• using a remote tool may not capture all relevant info-seeking behaviour

  useful to include think-aloud tasks (cf. Luger et al., 2014; Macias et al., 2017)

• choice of search engine may influence search returns

• value of online info-seeking may depend on e-health literacy

• HCPs could promote vetted health websites such as NHS Choices or Cancer Research UK
Thank you!

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